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ABSTRACT

The fifth of five volumes on the means by which Canadian communities can reduce the incidence of mental retardation, minimize existing impairment, and improve the quality of life of the mentally retarded, this booklet focuses on issues raised by the first four volumes, discusses the current system of support and services in Canada, and offers recommendations. After an introduction, sections deal with the following topics: the nature of handicapping conditions and circumstances; rights and responsibilities; current conditions and possibilities; rights and values; the mandate and agenda; planning; funding (the Canada Assistance Plan, the Vocational Rehabilitation of Disabled Persons Act); assuring quality (the role of government); support circles and brokers; community members and professionals; characteristics of people who influence change; where changes are happening and where they should be happening. (DB)

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MAKING A DIFFERENCE:

What communities can do to prevent mental handicap and promote lives of quality

Volume V: Lights, camera, action

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MAKING A DIFFERENCE
Lights, camera, action

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CANADA

MAKING A DIFFERENCE:

What communities can do to prevent mental handicap and promote lives of quality

Volume V: Lights, camera, action

National Institute on Mental Retardation

NOTE

The examples and stories in **Making a Difference** are about real people and real situations. In some cases the names of individuals have been changed to avoid unwanted attention to families and children. We do encourage you, however, to contact us at NIMR if you would like to receive more information on a specific example or story.

Dedication

Making a Difference is dedicated to Dr. Ronald J. Christie who spearheaded the involvement of the National Institute on Mental Retardation in the field of prevention. His death, in 1985, was a blow to the movement for persons with mental handicaps. Among his other accomplishments, Dr. Christie had also been an NIMR Associate, a former Vice-President of the Canadian Association for Community Living, a past President of the Metropolitan Toronto Association for the Mentally Retarded and a member of the American Association on Mental Deficiency.

Dr. Christie was a general practitioner in London, Ontario and a member of the Faculty of Medicine at the University of Western Ontario.

We believe that **Making a Difference** is a manifestation of Dr. Christie's hope that NIMR would take a leading role in not only helping to prevent mental handicaps, but also in promoting lives of quality for persons with mental handicaps.

Photographs

The photographs in Making a Difference are meant to illustrate certain situations and do not necessarily represent specific individuals or events. Photographs of specific persons, however, are acknowledged.

Credits - Volume V

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PREFACE

In May, 1983, the Canadian Association for Community Living (formerly the Canadian Association for the Mentally Retarded) convened a group of approximately twenty people from across Canada in order to review developments in the field of prevention, to discuss the role of CACL and its member provincial and local associations in the field of prevention, to gain a better understanding of the role of the federal government in the field of prevention, and to develop a feasible action plan for future CACL involvement in this area. This symposium, made possible largely through a grant from the Health Promotion Directorate of Health and Welfare Canada, was the culmination of several years' work on the part of CACL. Since 1976, CACL had had a committee responsible for the area of prevention, and in 1979, when the CACL's Board of Directors conducted a major self-evaluation of the association's goals and structure, prevention was identified as one of the major directions to be undertaken by CACL.

The national symposium concluded an extensive two-and-a-half year consultation process with all regions of Canada through which a nationwide consensus had developed regarding the need for CACL to serve as a national coordinator and clearing house for information as well as a lobbyist at the federal level and provider of technical support. CACL would be supported in this role by its National Institute on Mental Retardation.

A significant contribution to the conceptualization of the problem was made at the symposium by Ron Draper of Health and Welfare Canada. Mr. Draper outlined a prevention strategy model developed by the World Health Organization (WHO) which he applied and adapted in his Directorate. Indeed, it was the presentation of this model which enabled the symposium to integrate CACL's interest in prevention within the context of the organization's overall concerns.

The WHO model suggests that prevention strategies can be implemented at four levels: the level of impairment, the level of disability, the level of handicap and the level of feedback.

Impairment refers to a physiological or psychological loss or abnormality which would impair physical or mental function. Disability is a consequence of an impairment or a circumstance which prevents individuals from performing their social roles. Handicap refers to a disadvantage resulting from an impairment or disability that limits or prevents the fulfillment of social roles. The concept of feedback refers to situations where further impairments and disabilities are acquired as a result of handicapping circumstances.

This approach fit in very well with CACL's concerns which focus primarily on individuals living with a mental handicap. Consequently, the notion of working not only to prevent impairment from occurring but also to minimize existing impairment and promote lives of quality for individuals provided the impetus for **Making a Difference.**

Although in **Making a Difference** we do not use the WHO terminology in such a specific way as described above, the WHO model provides the framework for these publications.

Making a Difference is a series of five monographs which address how communities can reduce the incidence of impairments which cause mental retardation and also how they can reduce those disabilities and handicaps which are environmentally caused – often by where people live or work or go to school.

A heartfelt thank you is extended to the Prevention Project Resource Team who developed the framework and content of this series, and to the staff of the National Institute on Mental Retardation for producing the final documents.

Sincere appreciation is offered to Dr. Maureen Law, Associate Deputy Minister, Health and Welfare Canada and to Mr. Ron Draper, Director General, Health Promotion Directorate, Health and Welfare Canada, for their support and direction in the process which we hope will "make a difference" for thousands of Canadians.

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and
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INTRODUCTION

Making a difference: what communities can do to prevent mental handicap and promote lives of quality is a series of publications aimed at assisting and encouraging action by individuals, groups and governments to ensure that, whenever possible, citizens of Canada do not acquire mental handicaps and that when they do, they are supported to develop to their potential.

The first volume of the series, **Planning for change,** is an overview of the types of conditions which can lead to mental handicap, what we can do to prevent these conditions, and how we can promote lives of quality for people who have handicaps.

The second volume, **The well-being of babies and young children,** looks at the kind of action that we and our government can take to keep ourselves and our babies healthy. Having a certain lifestyle, identifying and responding to possible handicapping conditions early, and making sure that babies and children with handicaps remain with their families in the community, are all essential to preventing handicaps and promoting lives of quality.

Helping children to live, learn and grow in their communities is the theme of the third volume which focusses mostly on the education of children with handicaps and ways in which they can be educated alongside their non-handicapped peers. The volume also emphasizes the importance of living with families and belonging to the community.

The fourth volume, **Respected and responsible citizens,** deals with the prevention of handicapping conditions in adults and what we can do in the places where people live, learn, work and participate in the community.

This fifth and final volume, **Lights, camera, action,** looks at the issues raised by the first four volumes, discusses the current system of support and services in Canada, and suggests how we can bring the pieces together to make a difference in people's lives and prevent further handicapping conditions.

Traditionally, discussions of prevention have focussed on conditions and individuals, mostly in medical or physical terms. Changing views, however, have added new dimensions to our understanding. We now realize, for instance, that when a person is born with or acquires an intellectual impairment, that is not the only important thing about that person. We must also look at the abilities and potential of the individual and respond to those qualities in a supportive way.

Our discussion of the prevention of mental handicaps and the impact of those handicaps on the lives of people has examined two areas of activity:

Preventing:

- the occurrence or impact of conditions which cause mental handicap;
- the circumstances, actions and practices which cause people with mental handicaps to become socially disadvantaged, isolated and unable to perform social roles; and
- the conditions, circumstances and practices which cause people with mental handicaps to acquire further handicaps and become even more dependent.

Promoting:

- the autonomy and strengths of the individual;
- the access of individuals to support and opportunities which enable them to perform social roles more competently;
- the adaptation of social and physical environments;
- the view that persons with handicaps are whole people with rights and responsibilities.

The nature of handicapping conditions and circumstances

Just as we have realized that people with mental handicaps should not have their lives defined by their handicaps, we have also realized that what, in fact, handicaps people has two dimensions:

- **the person's abilities and disabilities** – those things that make our bodies and minds work, which either allow or stand in the way of our getting on in the world; and
- **the nature of the world itself** – those things that make the world work which allow us to use and develop our strengths and overcome our limitations.

As far as abilities and disabilities are concerned, there are many known and unknown causes. It is estimated that about 50 percent of the causes of all cases of mental handicap are unknown. Recent advances in this area, however, have been significant.

As our understanding of the initial causes of mental handicap increases, so does our knowledge of handicapping circumstances. There are many types of handicapping circumstances which stand in the way of people participating in the world. Such circumstances fall under three types of conditions and practices:

- those which prevent individuals from developing skills;
- those which prevent individuals from performing social roles; and
- those which cause additional health and emotional problems.

Some examples of actions which are likely to result in handicapping circumstances are:

Failure to diagnose

- failing to diagnose or identify mental handicap or improperly providing treatment when diagnostic methods are known.

Failure to treat

- withholding adequate immunization, or denying lifesaving or corrective surgery for people with neural tube defects or Down syndrome or a severe mental impairment.

Failure to serve

- exposing individuals to environments which provide neither affection nor stimulation, and denying them access to therapeutic services which they may need;
- denying people access to positive environments either for social reasons (for instance, low expectations) or physical reasons (lack of wheelchair access, attendant care or accessible transportation);
- inappropriate or too much medication which causes additional problems.

Failure to develop abilities

- teaching individuals to develop skills and abilities which are not useful in their lives, at the expense of learning useful skills or adapting the environment so that a person can do things with assistance.

Discrimination

- denying employment, housing and educational and social opportunities because of prejudice, segregation or congregation, and low expecta-

tions, either overtly or subtly.

Rights and responsibilities

Canadian and international law is clear – people with mental handicaps have the same rights, freedoms and responsibilities as other citizens, and have the right to equal protection and benefit of the law. As citizens, people with a mental handicap should be respected, protected and supported so that they meet their responsibilities and exercise their rights and freedoms through:

- Membership: actually belonging to a family, a neighbourhood, a school, a workplace, a community;
- Citizenship: having rights respected and being supported to meet responsibilities; and
- Determination: having control over life and body and decisions which affect the quality of one's life.

Most of us know or know of someone with a mental handicap through friends, relations or work. All of us, as taxpayers and citizens, participate in creating environments which either stand in the way or promote the presence of people with handicaps in our lives. Communities, schools and workplaces stand to lose a positive dimension without people with handicaps. Such places have found a richer and more worthwhile existence when they involve people with handicaps.

What is current? What is possible?

All too often our society and communities are not systematically doing what we know is possible to prevent mental handicaps and promote lives of quality for citizens with mental handicaps. All too commonly the pattern of support that is provided is only in the form of services which are funded and designed by government. These often further handicap our fellow citizens, family members and friends by segregating them physically or socially.

Lifestyles
There should be public policy and programs to create safe work places, a healthy environment, safe highways and health education for high-risk prospective parents. Too often, there are no systematic approaches to make this happen.

Early response
There should be screening, diagnostic, counselling and treatment programs which support and encourage families with a handicapped child. Too often, such programs are not available and quality, comprehensive health care systems are not in place.

Family building
Every effort should be made to support families to remain together and to keep their handicapped child at home. Too often, parents are advised to give up their child or to have their parenting roles taken over by services or professionals.

Education
We now know that children with even the most challenging needs can receive a quality education and develop a sense of belonging alongside their non-handicapped peers in the same classrooms. Too often, children with handicaps are

segregated in special classes or not educated at all.

Adults with mental handicaps can also benefit from the kind of adult education that is routinely available to others in the community. Too often, this possibility for integration and learning is ignored.

Places to live

It is possible for all children to live either with their own families or with alternative families. Too often, children live in institutions or in group homes with only other children with handicaps as models and friends.

Adults with even the most complex needs can be assisted to live in co-operative environments with non-handicapped people. Too often, adults with handicaps are grouped together with little or no chance for independence and autonomy.

Work

Recent developments in the area of work for people with handicaps have shown that people with the most challenging needs can be supported in meaningful, integrated (and often gainful) employment. Too often, people have been relegated to sheltered, segregated employment where they are forever being "prepared" for work.

Participation

With appropriate assistance and support, people can participate meaningfully with other non-handicapped community members in all kinds of cultural, recreational and leisure activities. Too often, even if individuals live in the community, there are special activities designed for people with handicaps.

Determination

Individuals can and should be able to express their preference in terms of where and how they live, learn and work. Too often, they are not encouraged to make their wishes known or they have token participation in decisions which affect their lives.

Current policies and services aimed at preventing mental handicaps and promoting lives of quality tend to focus on specific areas – "early intervention" services, "residential" services, "vocational" services and so on. The problem with this approach is that individuals and families are often not seen as whole beings with a past and a future that need to be taken into account.

One way of seeing people with handicaps as individuals with many dimensions is by describing or "drawing maps" of their experiences and relationships (Mount, 1984).

To illustrate this technique, but more importantly to show the connections among various aspects of people's lives, let us introduce you to three people – Marian Bishop*, Joannie Tanaka*, and Catherine Schaefer – and some "drawings" of the life of one of them and its potential for change.

Marian Bishop is 14 years old. She has a loving family and, what many would call very challenging needs. Soon after she was born, a psychiatrist recommended that Marian be placed in an institution because her mother was under a great deal of stress and was not receiving any support.

For ten years, her life was pretty much the same: she was confined to bed in a faraway institution 24 hours a day. Decisions about her life were made mainly by professionals without any family involvement.

Recently the family has become more involved and a few more people have entered Marian's world: her mom, dad, brothers and sisters want her to move closer to home; a number of government officials and agencies also want her to move closer to home; and various friends are supporting Marian's family to return Marian to the community.

Marian's future is still "in process." Although she is still in the institution, a different "map" is in the works for her future.

Joannie Tanaka is six years old and has needs similar to those of Marian Bishop. She relies on others for most things – bathing, diaper changes, cooking and eating, preparing and taking medications, exercising, using her posture board, going to bed, going to appointments and so on.

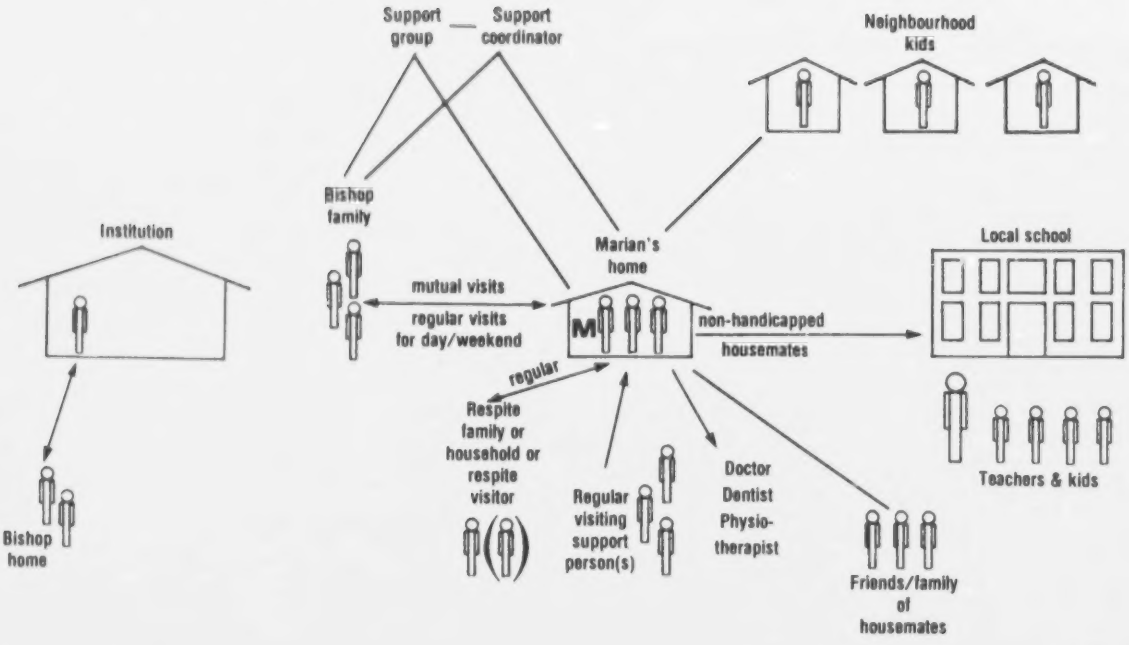
She lives with her family and goes to the local daycare centre with other kids in the neighbourhood. Her mother and a person from an agency which supports families to obtain necessary services are working to have Joannie attend the local elementary school. She spends a lot of time going to doctors and physical therapists. She also spends time out and about in the neighbourhood with her sisters. They can tell you more about the kids who know and care about Joannie than her mother can. Her mother and sisters spend time with Joannie doing exercises, learning to crawl, listening to music, reading stories and getting on with the business of being a family.

She visits her grandparents on a regular basis, sometimes staying over. Joannie's mother gets a

**pseudonyms*

CURRENT

FUTURE



lot of support from her parents, several neighbours and the person from the agency.

If Marian Bishop and her family had received the kind of support Joannie Tanaka and her family have received, her map might look much like Joannie's.

To some people, Catherine Schaefer is a lot like Joannie Tanaka and Marian Bishop, only older. She is in her early twenties and until recently lived with her family in Winnipeg.

Catherine's parents had often been advised to institutionalize her but they were always adamant about her remaining a member of the family. Through the support of friends, Catherine now has a solid network of relationships that has allowed her to move into her own house with non-handicapped housemates. Her home is equipped with ramps inside and out so she can get around in her electric wheelchair and she has access to a van with a lift so she can get out of the house and around the city. She also goes to the local community college with some other friends with handicaps.

The life experiences of these three individuals demonstrate some of the ways that things work together. Or don't work together. Some of these individuals have experienced dramatic changes, or they are hoping for changes, in their lives. The places and the people with whom they relate are rich and complex. They have different identities amidst a network of people. They are fellow workers or students, friends or family, customers or producers, kids on the block, clients or patients, tenants...

Nevertheless, we always run the risk of defining what's a good and rich life for people with handicaps in ways that are different from our views for other people. Take a few minutes. Draw your own map in relation to the community. Compare it to the situations of people with handicaps you know. Notice any difference?

Life is complex. Getting a perspective on how things can work together or seeing the big picture sometimes means putting things together in different ways. Depending on your perspective, the big picture now can look gloomy or hopeful. We have tried to be clear about the shadowy sides of the reality in Canada, but also to offer examples of light.

THE BIG PICTURE, THE IDEAL SCRIPT

How can the big picture be put together? How can people with mental handicaps, their friends and the professionals who work with them make all the pieces fit and all the scenes come together into a coherent whole? Entire service systems have grown and taken shape without adequate attention to the real "people" needs of individuals and their families. Instead, they have only seen and provided for the "service" needs. Trying to make sense out of such a system as well as to encourage new approaches for helping people become members of communities can be, at the very least, a trying experience.

There are many services, government departments, organizations and professional people who have made it their life's work to help people with handicaps. Sometimes they are successful and sometimes they are not.

People with handicaps, their families and their friends need to understand what the current system can and cannot offer and how they can mobilize the resources that are available and sometimes create new ones, in order to put together their big picture.

We know what is possible. We know a lot about the capabilities of people with mental handicaps, their families and their communities. We have the experience, the values and the technology. The challenge is to make these possibilities into reality.

In Volume IV of this series, *Respected and responsible citizens,* we discussed those rights and freedoms which are recognized in the Charter of Rights and Freedoms and international law and apply to all citizens, including those with mental handicaps.

Those rights include:

- Equal rights, worth, dignity, protection and benefit of the law.
- The right to work, pay and the pursuit of a livelihood.
- Freedom of association.
- Life, liberty, development, security and support.
- Equal opportunity and quality services.

Statements of rights and freedoms, however, only give a direction for action. There must also be underlying principles to guide the action which will ultimately prevent individuals from being handicapped further and enhance their quality of life.

Individual power: people should have power over decisions which affect their lives, including the planning and evaluation of the support they receive, the people they live with and the work they do.

Family power: families should have similar power where their sons and daughters are concerned. When families are unable to make decisions in one specific area, guardians can take over for that area and not for a person's entire life.

Interdependence: people should be supported not only to be as independent as possible but also as interdependent as possible.

Positive environments: supports should be received in the most enhancing and least restrictive, natural environments which are adapted according to a person's needs.

Appropriate services: when services or programs are needed, they should be integrated, relevant, coordinated, consistent, individualized and should not replace natural relationships or settings but rather support them.

Now what would the ideal big picture look like? What are the key elements of the best of all possible worlds?

Ideally, as we discussed in Volume II, *The well-being of babies and young children,* every measure should be taken so that babies are born healthy. If there is an indication of a problem, it should be attended to as early as possible.

Families should be encouraged by family physicians and other professionals to develop their child's potential and to make him or her a real member of the family. Advice and help to the family about meeting more specific needs of the child should be readily available through regular health channels. Parents should not have to make extraordinary efforts to obtain supports.

Schools should provide integrated, quality education for all children, including those with handicaps. They should also prepare teenagers and young adults for the world of work, citizenship, and participation in the community.

Businesses and community organizations should be prepared to employ and receive people with handicaps as contributors to their efforts.

Adults should have the opportunity to live as independently and interdependently as possible with the people they choose.

And at every step along the way there should be friends, neighbours and family providing encouragement and support.

Well, we don't know about you, but we personally do not know many people, handicapped or not, whose lives follow this ideal script or who have such control over their existence.

The script of anyone's life has too many variables, too many unexpected turns to be predictable and consistent. So how can a script be developed for individuals with a mental handicap that will meet their needs, prevent further handicap and develop their potential?

Because the traditional response of our society to persons with a handicap has been segregation, there has been great reliance on *services* to individuals and their families. Even with more people coming out of institutions and into the community, the response to meeting people's needs is still often only service-oriented.

We have not had what John McKnight, a professor of communication studies and urban affairs at Northwestern University, calls "community vision." McKnight says that this vision, "understands the community as the basic context for enabling people to contribute their gifts. It sees community associations as contexts to create and locate jobs, provide opportunities for recreation and multiple friendships and to become the political defender of the right of labelled people to be free from exile."

Beyond our usual responses to individuals, McKnight says, "is the constellation of community associations - the church, the bowling league, the garden club, the town paper...the hardware store and the township board. [Here is] a society where those who were once labelled, exiled, treated, counseled, advised and protected are, instead, incorporated in community where their contributions, capacities, gifts and fallibilities will allow a network of relationships involving work, recreation, friendship, support and the political power of being a citizen." (McKnight, 1985).

A script then, has to take into account this "community vision" and use it as a basis for responding to people's needs.

The script can also include the more formal or service-oriented approach to ensure that the other important supports are available.

It is essential for anyone who wants to improve the lives of people with a mental handicap to understand the current system through which people are being served or not served. It is equally important to think about how this system can be adapted or changed to better meet the needs of individuals. There are many initiatives that groups, associations or individuals can take within their own communities to better people's lives. In the next section, we describe the way the system works and describe some of these initiatives.

HOW DOES IT HAPPEN? HOW SHOULD IT HAPPEN?

As we have said before, our lack of "community vision" has taught families and individuals to depend on professional services rather than on their larger community for support, the way non-handicapped people do. These services are often funded and/or operated by governments who are then in a position to control the very lives and lifestyles of people who depend on them.

We, in Canada, have become accustomed to such notions as hospital insurance plans, unemployment benefits, social assistance, pension plans, child benefits and other social programs that we like to know are there even if we don't need to use them.

We also know that these programs are by no means perfect and that there are constant complaints from citizens about the drawbacks of such programs. Many of us are often indignant about how governments use "our tax dollars," and take it upon ourselves to alter or influence government decisions and policies.

Before we can take any action, however, we need to know what the system is and how it works. And, as far as people with handicaps are concerned, how we can make sure that the money being spent is really making a difference in people's lives and preventing further handicapping conditions. We also need to know if these services are being provided in harmony with the building of supportive communities that can welcome people with handicaps.

As citizens who want to make a difference, we can make sure that federal and provincial governments have the following in place:

- a clear statement of rights, values and principles to identify what is important and right to do;
- an agenda of what must be accomplished;
- a clear mandate to meet the agenda;
- a system for planning;
- a plan for acquiring and distributing adequate funds to meet the agenda;
- ways to ensure that what happens results in quality and in a timely fashion;
- ways to ensure that there are sufficient numbers of qualified people to implement action.

Rights and values

Provincial and federal legislation often states very clearly the rights and values it embodies. Many provinces have passed laws stating that families should be supported; that children have a right to have all their needs met in the community; that all people have a right to health and social services; and that handicapped people should live in the least restrictive environment.

In addition, most provincial legislation affecting human services gives a clear mandate to ministers of health, social services and education, to act.

So, many governments officially espouse the values that would make a difference and have the mandate to do just that.

Mandate and agenda

Unfortunately, the ways in which governments have chosen to act – the ways they have provided funds, the priorities they have set, the agenda they have tried to meet often have not been within the context of their values and mandate.

Preventing mental handicaps and promoting lives of quality requires systematic action. The agenda of governments in Canada has been far from systematic. Despite all the statements of rights and values, governments have historically chosen to exercise their mandates in three fundamental ways with respect to people with mental handicap:

- providing institutional services;

- providing special segregated and congregated educational programs;
- providing segregated community-based services (primarily residential and vocational) in response to crises.

Government agendas have usually been formed as part of the budget submissions of specific departments of government. Each program area lists the projects and programs it will fund in the coming year. Such lists apparently are not developed with reference to an overall agenda, specific objectives are not related to the province of a community as a whole, and there are no connections among programs in terms of lives of individuals.

But there are some indications that this is changing. Perhaps the most dramatic area in which governments are beginning to develop agendas is in the area of deinstitutionalization. Increasingly, in province after province, specific agendas are being developed to close institutions or to reduce their size, and develop community services to replace them. In Newfoundland, British Columbia, New Brunswick, Ontario and Quebec, for instance, there are plans to close institutions by certain deadlines. In other provinces, similar plans have been developed to reduce the size of existing institutions.

In some cases (Newfoundland, New Brunswick, British Columbia) there has been an added commitment that community services will be developed to ensure that those who leave institutions do not have to return, *and* that those who live in the community will not have to leave it.

In some provinces, similar things are happening in education and health. In Newfoundland, all children with mental handicaps now attend regular schools. In Ontario, there is a plan to develop regionalized health care delivery across the province.

Many of these changes have come about as a result of formal and informal lobbying by groups working with and on behalf of people with mental handicaps. For example, the diligent efforts of the Quebec Association for the Mentally Retarded recently resulted in the announcement of a major deinstitutionalization program by the Government of Quebec.

The persistence of families and British Columbians for Mentally Handicapped People also succeeded in reversing the policy of the B.C. government which had insisted on maintaining people with more challenging physical needs in institutions despire a major deinstitutionalization effort.

British Columbians for Mentally Handicapped People analyzed its successful approach in the following way:

Stage 1: Establish regular contact with civil servants and present your issues clearly.

Stage 2: Should the issue require a political decision, present it to the appropriate Cabinet minister in a courteous manner.

Stage 3: If an impasse results, contact other Cabinet ministers and the Social Services Committee of Cabinet. Keep the Opposition informed of the issue as well.

Stage 4: If all else fails, bring the issue to public attention through use of the news media or the court system. (Clark, 1984).

The New Brunswick Association for Community Living (NBACL) played a major role in that province's decision to get people out of institutions, to develop community alternatives, and to make sure that people already in the community remain there.

The strategy developed by the association was to move on different fronts, step by step. Before change could be made, however, political will had to be created within the government to change its response to people's needs.

The association gathered information about government policy and practice and then brought the need for change to the attention of authorities. For example, the association focussed on the inequities and injustices faced by families; it mobiliz-

ed efforts around situations which were embarrassing to the authorities; and it suggested studies that built a case for change.

Then NBACL had to make sure that it would continue to play a meaningful role in the process in order to safeguard it. This took the form of such activities as making sure that families were supported to participate in planning for their handicapped members; that there was local involvement in planning and implementing supports; and that NBACL participated in regional planning and implementation.

So, once it had provided an impetus for action, the association took on a monitoring, safeguarding and assurance role. (McWhorter, 1986).

Associations then, can very clearly influence and sometimes determine the way in which governments set their agenda and carry out their mandate. The key is for neither party to work in isolation but rather as a team whose goal is to enable communities to meet the needs of all of their members.

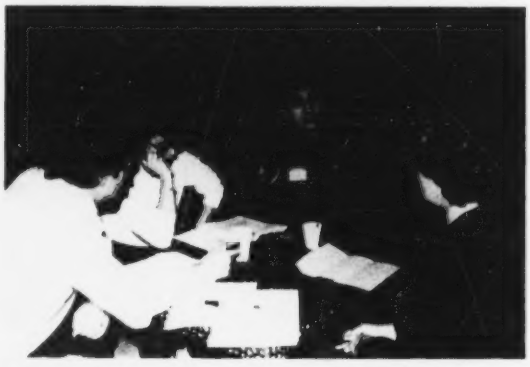
Planning

Inasfar as governments are most often responsible for funding the more formal supports that a person receives, they must ensure that these services are delivered in a systematic way. Service planning is an important tool that must be in place before the service needs of an individual can be met. Planning must occur at several different levels:

- overall policy within the federal and provincial governments, cutting across departmental lines;
- overall policy within each department;
- at the regional level, whether those regions are national or provincial;
- within service agencies;
- at the level of families and individuals.

Two streams of planning must occur and reinforce one another:

- "Top-Down": The development of policies, agendas, budgets, standards and review mechanisms at the level of the federal and provincial governments which will inform the activities of other levels of the community and determine the range of action available for an individual.
- "Bottom-Up": The most effective way of planning for supports which are responsive to the abilities and needs of individuals is to start by identifying what each individual needs. The information provided by quality individual service planning is essential for developing services for the individual and for a particular agency, community, region or province. In other words, only those services which are needed by individuals are developed and delivered. When they are no longer needed, they are not delivered. Using this "one-at-a-time" approach, it is possible to develop plans for increasingly larger groups of people without losing the individual nature of the planning process.



Planning for individuals – planning for communities, regions and provinces

As we have said earlier, an individual plan is a tool for meeting the *service* needs of a person. It is by no means a comprehensive map of a person's existence. In fact, there are many richly funded service systems with mandatory individual service plans which come nowhere near to meeting all the needs of the people they serve. We all need friends, neighbours, family and colleagues to fill in the gaps left by the services we may use.

Service plans are intended to describe what services are supposed to do. One of the things that services should never do is replace the natural and informal supports available to people. Services are intended to supplement a person's life, not define it. Effective planning must pay attention to a number of things that deal with the relationships between services and the more informal parts of a person's life:

- how can services and staff build relationships

between the individual and other members of the community?

- how can people who are already in the person's life (family, friends, pastors, etc.) become more effectively involved in meeting the individual's needs for a job, meaningful things to do in the community, a place to live?
- how can the individual's existing "connections" in the community be developed further; why pay someone to help develop friendships when there are plenty of people who would be involved if only asked?

As far as the more formal ways of meeting people's needs are concerned, there are a number of elements that must be identified in quality individual service plans in order for the service part of a person's life to make sense:

- the type and nature of the settings required (houses, jobs, classrooms, etc.);
- the demands which will be placed on existing services and opportunities in the community;
- the types and numbers of support people who will be required and the skills they will need to assist the individual;
- the goals and objectives to be achieved on behalf of the individual, who is responsible for each objective and by what time the objective is to be achieved;
- the amount and type of funding required to implement the plan;
- the types and amounts of professional support services required, such as physiotherapy or behaviour management.

By summarizing the requirements for individuals, quite specific plans can, therefore, be developed for:

- different levels of the community – the agencies which will serve and support those individuals, the community (in terms of the coordinated action of agencies in the community), the region and the province;
- different areas of services – for instance, the numbers and types of new places to live which must be developed within a year (in an agency, a community, a region, a province); the range of professional support services required; and the numbers of families requiring a certain type or certain amount of in-home support;
- gaining access to existing services, developing new services, and removing services which are no longer required;
- staff training and manpower development;
- financial resources required;
- policy and funding changes (within agencies and governments) which will be required to implement plans for individuals;
- the relationships which will have to exist among agencies and governments so that they can coordinate their activities for one or more individuals.

Once again, associations working with and on behalf of handicapped individuals at the local, provincial and federal levels can play major roles in helping to develop plans that will be in the best interest of individuals and based on sound values and principles.

Funding

In Canada, most services to people with handicaps are funded or operated by provincial or territorial governments. They, in turn, rely mostly on federal government programs which often determine how money will be spent.

This is a very complex area to discuss, but some examples will demonstrate some of the ways in which the system works.

The Canada Assistance Plan

The Canada Assistance Plan (CAP) is a federal government program. It permits the federal government to pay 50 percent of the costs of provincial and territorial governments' welfare and social assistance services provided or purchased by those governments.

The costs which are shared by the Federal Government are determined in three ways:

- an agreement between the federal and provincial government,
- provincial government decisions about which programs and services it will offer and fund,
- the eligibility of the individuals served by those programs and services.

As we have said earlier, provincial departments of social services generally spend the bulk of their funds on institutional services rather than on community services for people with a mental handicap. CAP will share the costs of "homes for special care," for instance, which are often large, impersonal and restrict peoples' freedom. Many of the costs for individuals in such "homes" can also be shared. In contrast, services which support children to remain in their families are very awkward for cost sharing and family income is needs tested to determine eligibility. Similarly,

"supported living environments" (such as apartment programs) may lose their eligibility for adults who have become employed and are no longer "in need" as determined by needs testing.

The Canada Assistance Plan is a permissive program – it does not require that service be provided by provinces. It is not tied into a specific agenda of the federal government. It contains no provisions for encouraging new directions. For instance, there is no incentive for provinces to dismantle institutional services. There are no special funds available to assist provinces to cover the extra costs of developing quality community services, and at the same time operate institutional services while community services are being developed.

Nevertheless, the permissive nature of CAP does allow provinces to be creative and can fund various types of programs.

The Family Support Program operated by the Department of Health and Social Services in Prince Edward Island uses CAP funding to support families with a child who has a mental handicap. The program provides funding for respite and babysitting resources and direct financial support to families for such things as special equipment, transportation, medical supplies, special diets and in-home services.

The Vocational Rehabilitation of Disabled Persons Act

The purpose of the Vocational Rehabilitation of Disabled Persons (VRDP) program is "to remove disadvantages experienced by disabled persons, to avoid their dependence on the public or relatives and to restore them to usefulness by making available to them appropriate vocational rehabilitation services so that as far as possible they are enabled to contribute to Canada by sharing the same opportunities and accepting the same responsibilities as other members of the community."

The federal government shares the costs of provincial vocational rehabilitation programs and services in the areas of assessment and counselling; restoration; vocational training services, employment placement services, staff training and development; and coordinating all activities in the province related to vocational rehabilitation.

VRDP can be used to pay for the goods and services necessary for the vocational rehabilitation of individuals. There are, however, a number of problems which have limited the use of this program for people with a mental handicap:

- To qualify for long-term social assistance, many adults with mental handicaps must be labelled "unemployable" which often translates into "unable to be rehabilitated" or unable to "engage in competitive employment."
- The emphasis of the program tends to be on "rehabilitation" and independent competitive employment. Once people are employed, supports are often withdrawn. There are no funds available for the long-term supports that some individuals with mental handicaps will require on the job. Recent changes in the federal-provincial government agreements, however, do allow for cost sharing or some home-oriented follow-up services.

As we have stated earlier, although provincial and federal governments often claim to be working toward community living for persons with handicaps, their budgets often do not reflect that. Considerable portions (and sometimes most) of social services, health and vocational services budgets are allocated to segregated facilities and approaches.

The major problem is not one of insufficient funds (although more funds are needed to serve more people), but rather of the way in which existing funds are being spent. The Canadian Association for Community Living (CACL) has proposed a way to overcome the obstacle of what to do until all funds can be channelled into communities.

CACL suggested that:

> "The Minister of National Health and Welfare considers establishing, after consultation with provincial colleagues, a special short-term deinstitutionalization thrust fund, together with national technical expertise to assist provinces as they continue programs of deinstitutionalization." (CACL, 1985).

In other words, a special fund is required to assist provinces in meeting higher costs while institutions are being phased out and community services are being phased in.

The absence of such a fund, however, has not

prevented several provinces from pursuing aggressive deinstitutionalization programs. Nevertheless, there are repeated concerns that such programs do not allocate sufficient funds to develop and maintain a community service system which will promote an acceptable quality of life for people with mental handicaps who are returning to the community from institutions *and* for those who have remained in the community.

Individualized funding

Even when governments channel their funds into the community rather than the institution, they still tend to fund *services* rather than *individuals*. This tendency often undermines individual planning and discourages integration and self-determination for individuals with a mental handicap.

The concept of individualized funding has received an increasing amount of support in recent years. Several provincial governments have introduced the concept in specific programs and support for increased consumer control over services has been growing. (Stainton, 1985).

The following is an example of how individualized funding can work.

The Community Living Society (CLS) in Vancouver has implemented an individualized approach that consists of three autonomous components:

- *a fixed point of responsibility;*
- *an autonomous personal network support;*
- *autonomous monitoring.*

The fixed point of responsibility is with a community board which is made up of members of a registered society. This board hires professional staff to act as "brokers" for individuals with a handicap and their personal networks.

The autonomous personal network support is a group of unpaid individuals who are committed to the person with the handicap. The family is usually at the core of this network which also includes friends and advocates. The role of the network is to help individuals define and communicate their needs and aspirations.

Autonomous monitoring refers to a group of individuals who are unpaid and unconnected to the service or the individual, who will monitor the services to ensure the individual's needs are being met in a respectful manner that safeguards their personal autonomy and well-being. This is seen as an adjunct to, not a replacement for, government monitoring of quality and fiscal responsibility.

The individual and the personal network work with the service broker to determine what the person's needs are and how best they can be met in the community. The broker then assists the individual and the personal network to negotiate with the government for sufficient funds to meet the identified needs, through the identified services. When a commitment of sufficient funds is obtained, the broker then negotiates contractual agreements on behalf of the individual, specifying the rights and responsibilities of all parties, and ensuring monitoring and access as part of the agreement. The individual eventually has an array of services guaranteed by contract and designed specifically to meet her or his needs.

There is no direct cash transfer to the individual, but rather a credit system. The contract with the service provider specifies the terms of service and the service provider receives the appropriate amount from the government. Credits are portable at the individual's discretion. (Stainton, 1985).

Assuring quality

No matter how much money is spent and how well-intentioned supports and services are, the lives of people may not be significantly altered unless there is a way of assuring the quality of those supports.

■ The role of government

As far as governments are concerned, they should be responsible for monitoring and evaluating the services they operate and fund. They must ensure that their actions have quality results and that they spend money consistently with their agenda.

Unfortunately, at present, there are no routine and systematic ways for governments to assure quality. The primary approach to quality assurance in Canada is for the government to set minimally acceptable standards, especially in terms of fire, health and safety, and ensure that an agency or service meets those standards when they first start their operations. There are periodic checks to see if the agency is complying with the standards.

There are two problems with this approach:

- Minimally acceptable standards do nothing to encourage excellence.
- Compliance with such standards, at best means no one is harmed or in an unsafe environment, but does little to ensure a better quality of life.

There are a number of actions which governments can take to ensure quality in the services they provide and purchase:

- Continue to set minimally acceptable standards, but relate them to more meaningful aspects of a person's life. For example, a person may be living in a perfectly safe environment but have little to challenge him or her, mentally or physically.
- Reward service providers for meeting or striving for standards of excellence.
- Require individual service planning firmly linked to rights and values and use such plans as the basis for monitoring and evaluating services.
- Recognize that monitoring is not the same as the traditional and formal practices of licensing and accreditation. It must be an ongoing process related to individuals and from a number of perspectives, not just that of government, and including the perspective of the consumer of services.
- Make sure that programs and services achieve what they say they will achieve, not merely provide a service with no specific goals.
- Rely on individual service coordinators or "brokers" as a vehicle for holding agencies and services accountable for meeting objectives specified in individual service plans.

■ The role of communities, associations and consumers

Although the government's role in assuring quality is an essential one, it is by no means the most important one. Families, friends, community groups, associations and consumers themselves are playing a growing part in monitoring services and supports.

In fact, parents' associations which have been working for years on behalf of people with handicaps and often provided their own services, are taking on the responsibilities of monitoring rather than providing services.

As we saw earlier in the section on mandate and agenda, provincial associations such as the New Brunswick Association for Community Living (NBACL) are showing how they can be effective advocates, lobbyists and monitors for people with mental handicaps and the supports they receive.

With 400 local and 11 provincial and territorial associations throughout Canada, these groups have been working on behalf of people with mental handicaps for over 30 years and their potential as monitors has been well documented.

The growing consumer movement and groups like People First are increasingly more articulate in expressing their needs and wishes and are often doing this through monitoring such areas as employment opportunities, wages and housing.

In our example on the Community Living Society, we mentioned the notion of autonomous monitoring which is carried out by unpaid monitors not directly connected to the service, the funder or the individual receiving the support. The monitor is responsible for ensuring that supports are focussed on the individual and that the individual's dignity, autonomy and self-determination are safeguarded. If they see a problem their job is to alert the family, the funder, the service provider or the broker, but they have no right to interfere with the service or the personal network. (Stainton, 1985).

The following section describes how individuals who may or may not have special skills are becoming involved in the lives of people with handicaps, helping to monitor the supports that are received and connecting people to their communities.

■ **Assuring the involvement of paid or unpaid qualified and competent people**

Supports or services provided to people with handicaps must involve qualified and competent people but that does not necessarily mean that they must have degrees or special diplomas. The most successful support people have often simply been community members who have been willing to involve people with handicaps into regular community activities.

For people with mental handicaps to be truly a part of our communities, it is necessary for many fellow citizens to be involved in their lives, not only as service providers, but as employers, friends, neighbours and family members. While these people often need little training, and may or may not be paid, there is a responsibility to ensure that they at least have the opportunity to be involved in making it possible for people with handicaps to participate in the community.

In general terms, we in Canada face two major problems:

- There has been an explosion in our professional knowledge about the *capabilities of people with mental handicaps,* especially those with complex and challenging needs, and the *capabilities of families, ordinary citizens, professionals and communities* to support people to live in the community with dignity. Unfortunately, there are many professionals currently working in the field and others in training to enter it, who do not have access to this knowledge. There is a considerable discrepancy between what is possible and desirable and the degree to which that knowledge has been disseminated. Training and retraining programs are lagging behind current knowledge.
- The policies and practices of governments and agencies often exclude, intentionally or unintentionally, a number of different kinds of people – families, relatives, employers, neighbours and so on – from participating in the lives of people with mental handicaps and bringing their "common sense" knowledge to bear on their lives.

To address these problems, a number of communities across Canada are taking action, sometimes with the assistance of government programs. The following are examples of such efforts. Unfortunately, we are not aware of examples of systematic efforts throughout a community or a province to deal with the training and retraining of professionals in may disciplines and the involvement of competent, ordinary citizens.

The G. Allan Roeher Institute (formerly the National Institute on Mental Retardation) and Frontier College have funded Annmarie Ruttiman, an integration facilitator with no previous professional training, to help Katherine Woronko become a real member of her community in Richmond Hill, Ontario. Katherine has some very challenging needs and until recently was isolated in segregated schools and environments. Annmarie's job at school was not to teach Katherine new skills, but to help her make friends. In the process, Katherine learned a lot about being a teenager.

An agency in Louisville, Kentucky called ***Choices**** *hires individuals whose job is to make connections in the community for people with handicaps. One of the staff people, Susan*, helped Sylvia* to make her connections by hanging around Hilda's*, a neighbourhood coffee shop. The two went there together around lunch time when there were lots of other people. Eventually, they got to know Hilda, the owner who wanted to know more about Sylvia. Susan suggested that maybe Sylvia could do the dishes for Hilda, just for a coffee. Hilda introduced Sylvia to other customers including Margie* and Cynthia* wo invited Sylvia to a fitness salon, to church and to bingo. They also introduced her to Mrs. Stevens* who owned a beauty shop where Sylvia got her hair done. Hilda, Margie, Cynthia and Mrs. Stevens also invited Sylvia to go with them on their annual trip to Florida.*

**pseudonyms*

WHO MAKES IT HAPPEN? WHO SHOULD MAKE IT HAPPEN?

"Support circles" and "brokers"

The responsibility for meeting a person's needs and ensuring his or her rights has traditionally been assumed by different people and organizations - the individual, the family, an agency, advocates and advocacy organizations and individual professionals. It has usually been the family or the individual, however, who has attempted to direct formal organizations (governments and agencies) and professionals to respect rights and achieve positive outcomes for individuals.

For the most part, families and individuals have had to make these attempts without much support. Frequently, but far from universally, they have banded together in associations or groups to support one another. Much more frequently, they have had to fight for what they wanted or have had to accept only what others were willing to offer. They had to rely on the good will, if not charity, of professionals, agencies and governments to supply what was needed to make their script a reality.

Groups of people have shown, however, that they do not have to be official representatives of agencies, organizations or governments to get the job done. They may be people who are personally close to the individual requiring support. They may in fact be a whole group of people who have gathered around one individual and his or her needs. More and more of these "support circles" are popping up all over the country and have proven effective for helping people, not only to get services they need, but also to help them become a real part of a network of friends in a community.

The Joshua Committee in Toronto began around the very challenging physical needs of a woman named Judith Snow.

Judith uses a wheelchair to get about and needs an attendant for all her physical needs. A few years ago she had a physical and emotional collapse after being forced to live in a chronic care hospital for four years. At the time, Judith had a full-time job but could not get funding assistance for attendant care so that she could live in her own home.

A group of concerned friends and citizens who cared about Judith's well-being formed a support circle called the Joshua Committee. They decided to help Judith get a functioning attendant care system to make it possible for her to return to the community. After a few months of aggressive advocacy, the committee was successful in convincing the Ontario Government to make funding available.

A paid coordinator was hired to find, train and schedule a group of paid and volunteer attendants.

The attendant care schedule includes five periods of care each day. These periods are a two hour morning session, one and one half hours at lunch time, one half hour at supper time, three-quarters of an hour at bedtime and an all-night sleepover period. These time slots are each filled by an attendant, and are flexible as to time and place. In other words, Judith can decide when she will get up, when and where she will have lunch or supper and what time she will go to bed.

The Joshua Committee still functions and has inspired similar attempts throughout Canada.

The concept of a support circle is defined by the following fundamental strengths:

- personal commitment to the person circled, his or her wishes and needs;
- flexibility;
- the development and protection of control by the person over his or her life;
- empowerment of the person through access to community resources and networks;
- support for monitoring funding.

Because it is often difficult for the circled person to express his or her true wishes, it is usually necessary to have a facilitator in the circle who can help. Such a person must be committed to the value of relationships in a person's life and must help members of the circle to value the circled person's wishes and plans.

In more formal situations, we have increasing experience with two different, though not mutually exclusive ways of decisively and actively involving individuals and families in making decisions in people's lives:

- systematic direction from the individual and families in the development, regular review and approval of individual plans; and
- authorizing individuals (professionals or parents, for instance) to be responsible for coordinating the implementation of those plans and monitoring and evaluating that implementation. These people are often called case managers, service brokers, or individual service coordinators.

Individual service planning processes should require not only the involvement of the individual and the family (or a friend, advocate or guardian) but also their approval. The individual and the family must have authority to direct the action. At best, this authority deals mainly with approving the plan, identifying things which have gone wrong (or well), how they might be done more effectively and approving new plans based on a review. Participation and approval, however, give no authority to ensure that action takes place according to the plan.

Particularly for people who need more than one kind of support and over an extended period of time, the business of coordinating action is complicated. A number of people and organizations are involved. Everyone involved needs to know what they need to do specifically, and what other people are doing that affects what they do. Things cannot be left to chance or improvisation. For these people to act as a team, in concert with one another, direction and coordination is required. A fixed point of responsibility which can take the form of a service coordinator can provide the coordination.

To ensure that action takes place, a number of issues should be considered:

- Frequently, when plans are developed in response to individuals, existing services need to develop new ways of doing things, or new services need to be developed to do new things, because the individual does not and should not have to fit into what is currently happening.
- Service providers or agency staff should not be individual service coordinators or brokers. They have their own interests to protect and these may conflict with the best interests of the individual or the requirements of the plan. It is difficult for a staff member of an agency to hold his or her agency accountable for not doing its job for an individual. It is also difficult for a staff member of an agency to get a picture of all the things going on in a person's life, especially when more than one agency is involved in that person's life.

The responsibilities, authorities and power of an individual service coordinator are important if there is to be any level of guarantee that services will respond to the individual. In fact, the best way to think of case management is as an extension of the abilities of the individual and family to ensure that services are both responsive and accountable to the individual. Individual service planning and coordination should not be seen as a process of manipulating individuals and families so that they will fit into existing services. Quite the reverse. In fact, individual service coordination or brokerage in a number of situations may only mean empowering the individual and the family to act on their own behalf with the formal approval of the relevant authorities.

In order to function effectively a broker or individual service coordinator must be:

- Independent of service providers, funders and free of other potentially conflicting interests.
- Able to effectively support individuals and their personal networks to articulate needs and strengths and determine what will happen to them in the future.
- Knowledgeable about community resources available to meet the range of needs presented by the individual.
- Able to stimulate the development of required services not currently available.
- Able to negotiate effectively on behalf of the individual with funders and service providers.
- Able to stimulate the development of required services not currently available.
- Able to stimulate and empower advocacy networks around individuals.
- Able to provide ongoing technical resources and training to service providers.

In many jurisdictions in the United States, in-

dividual service coordination is required by state law for all individuals requiring more than one service and over an extended period of time. In the United States and Canada, these approaches are being used routinely in deinstitutionalization efforts though often with less authority. The term "individual service coordination" is also used frequently without the safeguards described here.

Obviously, individual service coordination makes little sense if there are no services, no ability to develop required services, no clear identification of what is acceptable and what represents excellence, and no capacity to use information about what is working and what is not working. All these things are required if a difference is to be made in people's lives.

Most importantly, however, other *people* are needed to make people's lives full, rich and rewarding.

Community members and professionals

Throughout this series of volumes we have talked about people being directly involved in the lives of people with mental handicaps. We looked at how groups of people can take on the responsibility of service coordination (Joshua Committee). There are also the people who are ultimately responsible for turning dreams into reality. They give advice, do the work and design the places in which the action will take place.

In the context of a full and rich life in the community, there are basically two kinds of people involved:

- professionals (people who get paid for their involvement in the lives of people) and
- ordinary citizens (people who, because of who they are, where they live, the families they belong to, the churches they go to, the places in which they work, the volunteer work they have chosen to do and so on, come into contact with and become involved with their fellow citizens).

These people provide two basic kinds of support to the individual:

- formal support services (organized services provided by a variety of agencies to assist a person to live in the community – transportation, dental and medical care, education, mental health services, recreation/leisure time activities, income assistance, specialized therapeutic services, family support and residential and vocational services);
- informal support (support networks such as families, friends, neighbours and peer groups, or organizations such as churches, schools, work groups and clubs that offer friendship and assistance, help in problem solving and help in obtaining needed assistance. Often the person with a handicap both receives support and, in turn, offers friendship and help).

An unfortunate reality for many Canadians with a mental handicap is that they often get only one kind of support from one kind of person. Frequently, people who receive services (educational, residential or vocational) are often isolated in those services and only receive support from professionals. Because services and professionals are involved, they do not receive support from, nor are they meaningfully involved with ordinary citizens. Just as frequently, individuals and families must rely totally on their informal network of support because services and professionals are not available to them.

The compelling reality, however, is that

- most people with mental handicaps, for varying periods of time, need services or professionals who can appropriately respond to their needs, and
- all people including all those with mental handicaps need to be involved with and supported by a network of friends, family and associates.

Regardless of who these people are, professionals or ordinary citizens, they must share a number of characteristics in common if they are to be as meaningfully involved as possible – they must be caring, committed, competent, hopeful, hope giving and supported.

Characteristics of the people who can make it happen

They must be caring and committed. We do not mean "caring" in the paternalistic, charity sense, but in the sense of having a concern for and a stake in the quality of life experienced by an individual or individuals with a mental handicap. Not caring *for,* but caring *about.* Caring means being concerned about the individual, his or her rights, the values which should inform decisions about life, and the quality of life, both now and in the future.

Caring usually means being affectionate towards the individual and assertive with others on behalf of the individual. It means being principled.

Caring about and being committed to someone means assisting the person to be self-reliant, but also to be appropriately reliant on others in the same ways that we all rely on others. It also means doing things with, more than doing things for the person.

They must be competent. Being competent means learning and applying the best knowledge available, being open to new ideas and learning from others. Being competent means being creative and thoughtful about a person, as a person, not as a disability. We know a great deal about techniques and teachnology - things which have a major effect on an individual's life. But competence means applying good techniques in a principled way. Mark Twain once said, "If a person only knows how to use a hammer, all problems look like nails." Hammers can be used to drive home nails, or to hit people on the head. Being competent is knowing the difference.

Being competent does not necessarily mean being a professional, though some areas of competence may require professional education and degrees. In most cases, being competent means being intimately knowledgeable about the individual, knowing what to do to support the individual, and knowing when good advice is needed to figure out what to do. As discussed in Volume I, most parents are competent. Some need additional help or advice to be better parents. Many need to learn specific things which will assist them to help their kids who are handicapped to grow and develop.

Being competent means being thoughtful and creative, not just routinely doing the same thing over and over regardless of who the individual is. It means thinking ahead and figuring out how to get from here to there. In some cases it means making the best of what is available and in others, figuring out how to get what is needed and not settling for less.

Above all, being competent means knowing your community and how it works for ordinary citizens. It is important to continually be aware of the distance between the reality experienced by people with mental handicaps in so many areas of their lives, and the reality experienced by ordinary citizens. It is important to know how ordinary citizens use their community (for instance, how people actually find jobs) so that people with handicaps can be assisted to use the community in the same way.

They must be hopeful and hope-giving. We have given a great deal of attention to the importance of expectations in the lives of people with a mental handicap. Having and giving hope does not mean promising a cure for intellectual impairments or that the world will be perfect. But it does mean being aware of the best that is possible, what can be worked for and striving for it while helping others strive for it.

They must be supported. People with mental handicaps, like everyone else, need support. Those who provide them with that support in turn need to be supported themselves. This does not mean learning everything about everything. It does mean learning about the strengths and needs of people and how to respond to them. In a recent workshop on education, a classroom teacher commented that in order for her to teach children with special needs she would need advanced level courses about disabilities. In her community, there were fewer than a dozen children with special needs, one of whom would be entering her classroom. A number of people who know the child well were willing to help her develop an appropriate education plan for the child. She needed to know she had help and a good understanding of the child, not another degree.

- Professionals and ordinary citizens who provide services to the regular population need to be supported and trained to provide those same services to people with handicaps.
- Many of the services which professionals traditionally provide to people directly are more efficiently and effectively provided indirectly by advising and training the people who spend time with the individual on a regular basis.

Where and who are these people?

Throughout this series of volumes we have identified the many different kinds of people who may need to be involved in an individual's life. The following summarizes some of the observations made in previous volumes.

People at home:

- people who are good role models, who have something to teach and offer to the person with a handicap;
- as much as possible, people who are not handicapped;
- for children, people who make a family;
- people with whom the individual will develop meaningful and long-term relationships;
- people who have been chosen by the person with a handicap;

- people who are connected to their community and can assist the person in making friends and acquaintances and gain access to opportunities in the community;
- people who have access to good advice and assistance to learn what they need to know and to deal with crises should they arise;
- neighbours who can be good neighbours in good times and bad, lend tools, stay with someone, go trick-or-treating, walk to school or ride the bus together.

People at school:

- regular kids, regular teachers;
- regular people in the community who can provide opportunities for learning and assisting the individual to learn in community settings (bus drivers, employers, store keepers and other kids);
- friends at school who will also be friends outside of school and in the neighbourhood.

People at work:

- people who can assist adults (and young people) to figure out what kind of work they would like to do; find work consistent with those interests; learn to do work and get along at work, or how to change the environment so those things are easier to do; learn new skills when the job or the environment at work changes; and to find new jobs when needed;
- regular workers who may become friends both at work and outside of work; give a guy a lift when the buses are on strike; go out for lunch; go in on a lottery ticket; tell about a better job somewhere else;
- people who can help employers, co-workers and people with handicaps think differently about how work gets done; help out when things go wrong or someone has a question; or just be there (usually a phone call away) just in case.

People who get out and about:

- people who regularly teach other people to be physically active, have fun, or learn something new;
- friends and acquaintances from home, the extended family, the neighbourhood, school, work or the Friday night poker club;
- volunteers who are interested in becoming friends to individuals;
- people in all sorts of places in the community welcoming their fellow citizens with mental handicaps as church members, service club members or team members;
- people who have special knowledge about supporting people with mental handicaps who can help all of these people be who they are and do what they do with people with handicaps.

People who provide regular health and social services to the rest of the community:

- professionals doing what they do best for people but including people with handicaps;
- professionals with special knowledge about people with handicaps giving advice, assistance and training to their colleagues.
- specific professionals with special knowledge who are organized and available to other professionals and ordinary citizens (especially those who are intimately involved in the life of an individual with a mental handicap) to help identify the individual's abilities and needs, what needs to be done to build a future and how others should do those things; to be available to help prevent crises and deal with them when they arise.

People who help develop their communities to be better places:

- designers and builders to ensure communities are accessible to those with a physical handicap;
- people involved in economic development to ensure that new businesses are developed in the community and when they are that they involve people with handicaps; to ensure that when new businesses come to the community they know the contribution that people with handicaps can make; to ensure that people who are involved with helping people find jobs know about new businesses and developments in the community;
- people who are involved with planning services and developing community capabilities for other groups of people with handicaps so that efforts can complement one another;

- people who develop new housing and renovate old housing to ensure that people with special needs have access.

People who are concerned about protecting rights of their fellow citizens:

- lawyers and advocates;
- families and friends;
- groups of people who have banded together in organizations and associations specifically for people with mental handicaps and broader groups;
- specific people who have been recruited to stand beside an individual with a mental handicap to ensure that the individual's rights and best interests are respected.

People who organize and operate services:

- government officials;
- boards of directors;
- management personnel in agencies.

For many people with mental handicaps, all or most of these types of people will be or should be involved in their lives. They are the ones who will play the continuing role in day-to-day living.

Rights Now is a community development project sponsored by British Columbians for Mentally Handicapped People and funded by the Health Promotion Directorate of Health and Welfare Canada. Its aim is to provide links between people with mental handicaps and advocates in two or more communities over the next three years. The basic goal of Rights Now is the active participation of adults with a mental handicap in all decisions which affect their lives.

Through discussions with self-advocates around B.C., the project has identified a number of needs. People with mental handicaps want access to education, jobs, recreational and cultural activities, affordable housing and good transportation. Others need support in marriages or in raising children. More importantly, however, the project found that people mostly need friends. This is what can make a real difference in people's lives. (Rights Now project, 1986).

The project is helping to connect people with hobby clubs, literacy groups, church groups and other community organizations which have been approached to include people with handicaps as members according to their interests.

For example, one young man who has a great interest in computers has been introduced to a computer club. One young woman who likes animals is now a volunteer at the local SPCA.

WHERE IS IT HAPPENING? WHERE SHOULD IT BE HAPPENING?

Take a break. Go for a drive around your community. You will see all the places in which the action for people with mental handicaps should be taking place.

Take a test. Think about all the places you and members of your family spend time where there are a lot of people (say at least 100). In how many of those places do you regularly find at least one person with a mental handicap? We would expect to find one person with a mental handicap in any group of 100 people who have gathered together in the regular places in your community.

If the people are not there, where are they? Is it even possible for your community to find out where all the people are? If not, why not?

It is of course one thing to say that people with mental handicaps should be in all those regular places in your community, and quite another to design those places and activities so that people can, in fact, be part of them.

More and more public places and transportation systems are being made physically accessible to people who have trouble moving around, seeing and hearing. When those places are where people work, government funds are often available to make them accessible for an individual working there. How accessible are public places in your community? Are there funds available to make people's houses accessible?

There are people who say that we need special places for people with challenging medical needs. We have learned, however, that people who need to have oxygen available at all times, or who have serious problems with seizures or who cannot get themselves out of a bed, can still live in regular houses on regular streets in the community. We are learning that this can happen if those houses are designed appropriately and if the people who spend time in them know what to do.

There are also places that are designed in ways that assume people do their jobs in only one way. We have learned, however, that with a little thought and creativity, we can adapt those places for people who have some trouble. Both federal and provincial governments publish guidelines on how environments can be adapted.

We have also learned that places can be inaccessible to people with mental handicaps, or they cannot use the equipment in those places, because of the ways they have been taught. People with a mental handicap often have trouble learning and using what they do learn in a variety of situations (generalizing). Many educational and vocational services, however, teach people how to do things in only one location, or an artificial location, or with only one kind of equipment.

This causes problems. People who have trouble generalizing will have trouble crossing streets

if they only learned how to cross one street; they will have trouble working the stove at home if they learn to use a stove that is different from the one they have at home; they will have trouble working a cash register or buying groceries if they have learned on a wooden cash register in a make-believe grocery store at school.

We have learned that the best way to make places accessible is to teach people about those places and the things that go on in them in the actual places.

Many places are also inaccessible because services require people to learn pre-requisite skills before they are allowed to be in those places. They have to learn "work behaviours" before they are allowed to be in regular places of work. They have to learn to climb plastic stairs in a classroom before they are allowed to climb regular stairs. They have to be toilet-trained before they can go to the grade eight class with students their own age. They have to learn appropriate behaviours before they can go to high school.

We have learned that this is not necessary:

- Often a regular community environment will place appropriate demands on an individual so that he or she will behave properly.
- Regular community environments are the best places in which to teach people the skills they need in those environments.
- Regular community environments are the best places for us to determine what changes can be made so the individual can cope in that environment. If someone has not learned a skill in a reasonable length of time, it is often better to figure out a way to compensate for the lack of that skill rather than deny the individual access to the environments where that skill would be used.

A young woman in Newfoundland was in a special class in an elementary school. She screamed a lot. There was no psychological or behavioural consultation available. Meanwhile they "found space" for her in the local high school. On the first day of school, she entered the front doors with the principal, turned to him and said "Well, I'm in the big girls' school now. Guess I can't scream anymore." He said, "Right." She didn't.

Often people are removed from places in the community because their behaviour is considered disruptive and "special places" have been designed to correct the behaviour. We have learned that the best places to deal with challenging behaviours are the places where the individual actually spends time. It is also important that the other people in those places are able to assist the individual and provide models of appropriate behaviours. "Special places" are usually filled with people who have only one thing to teach – more inappropriate behaviours.

What we have learned is simple:

- the big picture involves all the regular places in the community where regular people spend time,
- the accessibility of those places to people with a mental handicap is usually more a matter of adapting those places, the things that go in them, the ways that we teach skills and behaviours, and the supports provided to the people in those places than a matter of the abilities and skills of people with mental handicaps.

Conclusion

The purpose of this volume in the **Making a Difference** series has been to look back at the discussions about change in previous volumes, and look forward to the ways that individuals and families, agencies and communities, and governments need to work together in a systematic fashion to bring those changes about.

Much of this volume has dealt with one issue – bridging the gap between the current situation and what we know to be possible and desirable – the translation of a dream into reality.

For this to happen, three important elements must be present:

An individual focus: ensure that services and supports to individuals with mental handicaps, and their families and those who stand beside them, are based on the abilities and needs of the individuals, respect individuals' rights and support them as participating and contributing members of the community.

Responsible government: ensure that all levels of government have clear and positive statements of policy about rights, values and principles; develop a mandate and agenda for action; and ensure that planning, funding, standards and qualified people are in place to implement that agenda in ways consistent with policy.

Supported communities and citizens: ensure that all of the people and organizations serving the community, both formally and informally, receive the supports they require, and are challenged and supported to achieve excellence.

The **Making a Difference** monographs have covered a great deal of territory. Throughout, we have tried to provide examples of individuals, families, communities and governments taking action consistent with the best of what we know about preventing mental handicap and promoting lives of quality. We have suggested some things that you can do to make a difference.

We hope that at least one thing will start to happen – individuals and groups of people will sit down to discuss what these monographs have had to say. They will think about the suggestions made and the implications of what has been discussed, identifying some important things to do in their community. And they will talk about what they can do tomorrow and the next day, and the day after that. We hope that individuals and communities will develop very clear dreams about the future, and the plans of action to translate those dreams into reality.

LIGHTS...CAMERA...ACTION...
MAKE A DIFFERENCE.

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